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RUNNING HEAD: EXPERTS BY EXPERIENCE INVOLVEMENT IN THE
CAREGIVING HOPE STUDY

Experts by experience involvement in dementia research: The Caregiving HOPE Study

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Abstract

Patient and public involvement is imperative to ensure relevance of research. There is a growing literature on the theoretical underpinning on patient and public involvement including level and processes of involvement. The aim of this paper is to describe a person-centred approach to involving carers, people living with dementia, members of the public and carer support workers, as used in the Caregiving HOPE study; and the influence of the approach on the study's research processes and outcomes. Patient and public involvement members were considered experts by experience and involved with study conception, design, conduct and dissemination. The level and nature of involvement was influenced by each individual's needs and desires which changed over the course of the study. The approach had a significant impact on study outcomes as evidenced by successful recruitment and engagement at a national level, but was not without challenges with greater flexibility required and fuller consideration of financial and time costs required. Benefits of the approach included strong engagement, improved outcomes (successful recruitment of seldom heard groups) and meaningful relationships between researchers and experts by experience. A person-centred approach is required with patient and public involvement to ensure involvement is not detrimental to those involved, is meaningful and enjoyable and has a positive impact on the research.

Key words:

*Patient and Public Involvement, *Caregivers, *Dementia, *BME, *south Asian

Background:

The involvement of patients and public in health service design and research has been driven by policy, patient and carer advocacy groups and the academic community. In terms of recent policy, the Health and Social Care Act (2012) obliges Clinical Commissioning Groups (CCGs) and NHS England to promote the involvement of the public on decisions which relate to their health care and treatment and to ensure patient and public involvement (PPI) and consultation in commissioning processes and services. The National Institute of Clinical Excellence (NICE, 1999) also states its commitment to PPI and reiterates that by working with patients and the public, it aims to produce guidance that addresses patient and public issues, reflects their views and meets their health care needs.

A noteworthy driver of PPI has been the increase in patient and carer advocacy groups, for example the Dementia Action Alliance (DAA) which operates at local, regional and national level, DEEP (Dementia Engagement and Empowerment Project), and TIDE (Together in Dementia Everyday) which gives a voice to carers. A number of dementia advocacy groups have adopted the motto ‘Nothing about us without us’ to actively promote meaningful involvement of people living with dementia and carers in dementia research. Finally, academic drivers have arisen from the setting up in 1996 of the national advisory group, INVOLVE, which had the remit of advancing research through public involvement. Funding bodies such as the National Institute of Health Research require evidence from applicants as to how patients have been involved in the conception of their research proposal and how PPI will be incorporated into their project prior to awarding funding. Consequently, all NIHR-funded research has some element of PPI.

Several systematic reviews have established that meaningful PPI creates various benefits for the research community and those involved (Brett et al, 2014; Hall et al, 2010),

including: an increased likelihood of interventions being effective, services meeting the needs of the community they serve, enhanced relevance of research questions and topics, improved effectiveness of research processes (e.g. data collection), the provision of an alternative perspective and a greater likelihood of research findings being implemented.

The current study

This article describes the involvement of carers, members of the public, people living with dementia and carer support workers in the Caregiving HOPE study- a study that explores how cultural obligation, willingness and preparedness to care influence carer wellbeing, whether this changes over time, and whether south Asian and white British carers demonstrate commonalities or differences in these. In addition, the study explores attitudes towards dementia and how willing and prepared members of the public would be to provide support for a relative with dementia in the future. The long-term goal is to provide an evidence base for designing interventions that enable carers to feel more prepared for their role. From the outset, it was deemed essential that carers, members of the public, and carer support workers from diverse cultural backgrounds be involved in study design, execution, and results dissemination.

Theoretical underpinnings of PPI in Caregiving HOPE

The theoretical framework most commonly drawn upon for PPI is Arnstein's (1969) ladder of citizen engagement which describes a range of levels of involvement from manipulation, to consultation, collaboration and full citizen power. Tritter and McCallum (2008) contend that the ladder focuses solely on power and does not consider effective responses to the challenges of PPI (Oliver et al, 2008). Morrow et al (2010) propose a value-based approach to improving PPI with an emphasis on processes as opposed to level of involvement. Based upon social theories of power and empowerment (Beresford et al, 2007) Morrow's framework includes two factors that influence PPI processes: personal factors (ability,

potential, sense of being) and research contexts (research relationships, philosophy of research methodology).

The current study utilised a combination of Arnstein's (1969) and Morrow et al's (2010) frameworks to develop levels and processes of PPI with a strong person-centred value base. The level of PPI (consultation vs collaboration) is based upon each person's needs and desires and an awareness that these change over time. Our approach considered the following values: individuality, independence, confidentiality, choice, partnership, dignity, respect and rights. The following definition of PPI was adopted: carers, people living with dementia, members of the public and carer support workers are experts by experience with a wealth of knowledge and experience who, with the lead researcher (SP), and her mentors, will explore methods of improving the experience and wellbeing of current and prospective carers of people living with dementia. All those involved with the research were considered members of the study team regardless of personal or professional background.

Aim:

This paper reports the process of involving a diverse range of experts-by-experience using a person-centred approach within the Caregiving HOPE study, and its impact on research processes and outcomes.

Method

People involved

It was deemed imperative that the Caregiving HOPE team be diverse in terms of ethnicity, gender and age. The key stakeholders identified at the beginning of the project included: carers, people living with dementia, members of the public (non carers) and carer support workers. The team included 12 non-academic members: six carers, three non-carers, two carer support workers and one person living with dementia. Nine team members were female and three were male. Team member age ranged from 20 to 80 years. Five members identified

their ethnicity as white British, four as British Pakistani, one as Myanmar, one as British Indian, and one as British African/Caribbean. Three of the members had an additional role of being an Alzheimer's Society research volunteer and monitored study progress, study expenditure and training of the lead researcher.

Design

The team decided from the outset that meetings should be organised by SP at key stages of the project to enable members to meet and discuss the design and conduct of the study. Prior to meetings, SP would liaise with team members to ensure travel and parking was organised and that food and drink preferences would be met. The tone of the meetings was kept informal to enable lively discussions. There was no obligation for members to attend (all) meetings and written comment or input was possible as an alternative. In between meetings, SP maintained regular contact with individual team members and often met members in informal settings such as their homes or local coffee shops. Indirect contact was also maintained via email and telephone, subject to member preference. A regular newsletter was distributed to all team members communicating study progress and providing members with the opportunity to share personal news stories.

Stages of involvement

Pre-study conception: The notion of carer preparedness and its influence was conceived by a carer. This carer had been involved as a participant with SP's previous research which had found that although south Asian carers perceived a higher level of cultural obligation to provide care than white British carers, they did not differ in willingness to care. Those south Asian carers who were highly willing to provide care were more likely to experience poorer wellbeing whereas highly willing white British carers experienced better wellbeing (Parveen et al, 2011, 2013, 2014). This led the carer to question whether the willing south Asian carers had not been prepared for the role and had been overly optimistic. The concept of

preparedness led to the development of the current study in which preparedness is a core focus. Further carers were involved with facilitating the production of lay summaries for the funding bid and ensuring the study was relevant to carers. Once funding was secured, the original carer helped to identify key stakeholders to build the team.

Study design and conduct: Potential members, through a series of one to one discussions were provided with an overview of what the study would involve, the key milestones and opportunities for involvement. Members then made informed choices about what aspects of the study they would be involved with and their level of involvement, with some deciding an advisory role would be more suitable for them due to caregiving, or other, demands whereas others became more actively involved. All members agreed to be part of the team, with SP as the main academic contact point. As SP came to know members individually, their skills and experiences were utilised for specific tasks, for example, two members with a background in marketing and graphic design worked with SP to ensure the study had a strong identity in terms of the ‘branding’, including name, logo, colours and imagery associated with the research. Another non-academic member, a student of clinical sciences in the process of choosing her undergraduate dissertation topic, elected to conduct a systematic review for the study (with guidance). Those wanting a more advisory role helped the researchers to develop the materials required for NHS ethics and provided advice on methodology. Their input was responded to, for example, based on the advice of a member, recruitment criteria for interviews were expanded to include ex carers as well as current carers. The carers and support workers were very well connected with third sector carer groups and also worked with NHS sites to facilitate recruitment. The Alzheimer’s Society monitors were particularly helpful in connecting the researcher with local Society branches and overcoming any barriers to recruitment. All members were involved in discussing study progress, findings and interpretation of data.

Dissemination: The study is ongoing; however, the team have prepared a dissemination plan with short and long-term impact goals. During the study, those members who had built large followings on social media facilitated study promotion. Members have also been promoting the study through personal networks and some team members accompanied the lead researcher on visits to carer groups and NHS sites to promote the study and also presented at local and national conferences. The team is currently designing and finalising the content for the Caregiving HOPE carers' book (a direct output for carers from the study findings) and is planning to apply for funding to hold a dissemination event.

Results: Impact of PPI

The viewpoints of team members with regards to their role are presented in table 1.

Insert Table 1 here.

Context and process of PPI

Factors that hindered and supported PPI in the current study are similar to those proposed by Morrow et al (2010). Personal factors (ability, potential, sense of wellbeing) were significant facilitators in the process, shaping what each person was able and willing to contribute. For example through one to one sessions with members, we were able to identify member's skills (such as design) and utilise them for the project. Three members were keen to present the project at conferences and at public events but perceived a lack of self-confidence. With the support of SP, they were able to present and this improved their self-esteem. An important facilitator was for SP to build relationships with members, as this enabled each team member to build knowledge of the project and trust in the PI, and so allow true involvement in tune with Arnstein's levels of consultation and collaboration. Contextual factors (research philosophy and processes) contributed to this; for example, explicit adoption of a person-centred approach permitted/encouraged SP to work in collaboration with the team to consider

and include a wide range of PPI contributions suited to each person's individual strengths, whereas a less explicitly person-centred philosophy might not have fostered such consideration of individual contexts. This person-centred approach meant that each PPI representative contributed according to his or her needs and wishes and so involvement was more likely to build well-being through a sense of empowerment rather than undermine it through a sense of being marginal. The study topic and outcomes were well suited to PPI as the central constructs (obligation, preparedness, willingness) could be readily understood and were directly relevant to the lives of PPI members, rather than being abstract or involving fundamental science. Some contextual factors were a hindrance to PPI such as university finance, travel and subsistence regulations which are not always person centred. The need for diversity meant that the group was larger than is usual for PPI, and managing everyone's expectations and relationships became difficult and time-consuming at times. For example, due to the size of the group, it was not always possible to identify a meeting date that suited everyone, and meeting members one to one was time consuming. A limitation of the funding bid prepared was non-costing of involving members at conferences and events and this therefore incurred additional travel costs highlighting the need for realistic planning. Also although translation costs had been accounted for when interviewing non English speaking participants, they had not been included as part of the PPI budget.

Outcomes and Impact of PPI

The principal tangible outcome of PPI in the Caregiving HOPE study was recruitment success, resulting partly from the widespread connections and energetic promotion of the study by the team. For example, in the first study, the target of 372 carers was significantly exceeded (723 carers recruited). Perhaps more impressively, among this large sample, 185 south Asian carers were recruited, with this being significantly influenced by the inclusion of experienced South Asian PPI panel members who were well connected with communities. In

the second (non-carer) study, the target sample of 500 adults was also easily met (approximately 1200 participants were recruited). The large sample sizes recruited in the study were due to the support of the PPI team, particularly with regards to the recruitment of the south Asian community. Of the 185 south Asian carers recruited, approximately 70 south Asian carers were identified via the PPI team and of the 250 south Asian non-carers, 154 were identified by the PPI team. The carers support workers were particularly useful in facilitating community engagement. Through PPI advice that ex carers should also be included in the first study, richer qualitative data was collected which allowed the research to explore transition points out of the carer role, such as at end of life care. The promotion that the study received (it was featured on various radio stations and BBC local news) was also in part due to team members acting as ambassadors for the project. Perhaps a less tangible impact of the study is the development of strong relationships between team members and the academic team, with members expressing a desire to continue being involved with research once the study is completed. Members will have the opportunity to join the wider Centre for Applied Dementia Studies experts by experience group (and thus increasing the diversity of the Centre's group) and also be involved in future grant applications building on Caregiving HOPE.

Discussion

The Caregiving HOPE study aimed to involve experts by experience (carers, people living with dementia, members of the public and support workers) using a person-centred approach to involvement. The approach appears to have worked well with significant influence on research outcomes and impact in terms of number of participants recruited, community engagement and outputs (a book for carers). Such a person-centred approach allowed flexibility in the level and process of involvement. Through this approach, the study was able to involve a diverse range of people in various research activities in a meaningful

way. This enabled significant recruitment successes and national level engagement that will also promote wider impact than would have been possible otherwise.

An additional goal was to ensure the representation of diverse groups within the team and to some extent this was achieved. All potential stakeholders were represented in terms of role (carer, members of the public), ethnicity, gender and age, although the three general public members were perhaps less representative as all were University students in their twenties. Their views may differ from older, non-student representatives who would have brought other perspectives, attitudes and skills from their different life experiences. In addition, although the voice of seldom heard groups (south Asian carers) was included, these individuals were well educated and English speakers. Further work is needed to ensure inclusion of non-English speaking groups who are currently under represented in health research. The approach used in the current study, for example meeting with members on an individual basis may be viable to including non-English speaking members as communication can be facilitated via translators on a one to one basis but acts as a hindrance to discussion in group settings. In the current study, the use of translators was costed in for recruiting participants but not for PPI which was an oversight.

The approach used within the current study involved some notable challenges. The approach taken of meeting members individually and also maintaining regular contact (via phone and email) between meetings was time consuming and required a great deal of flexibility in terms of working hours and travel. Despite the challenge, it was perceived the approach was necessary to maintain meaningful involvement and has been reported to be a positive by the team. Whilst a person-centred approach was in line with the values of the University of Bradford Centre for Applied Dementia Studies, it was not always in line with wider university policies and procedures. The policy of PPI claimants collecting their payments from University premises was problematic at times, particularly if activities were

off campus. Further institutional level barriers arose concerning meeting individual's food preferences (e.g. provision for vegan members and Muslim members being restricted to a vegetarian diet due to lack of Halal food provision), due to the requirement that only internal catering services could be employed. Access to training and university resources for members wanting to widen their knowledge (such as the library) was found to be challenging and involved a significant amount of bureaucracy.

Despite the challenges involved with adopting a person-centred approach to involving experts by experience in dementia research, the positive impact on the people involved and the research processes and outcomes outweighed the challenges. By using a person-centred approach to PPI, the study was able to successfully recruit a diverse group of participants, give seldom heard groups a voice in research through successful community engagement and produce tangible outputs for carers.

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Table 1. The perspectives of team members

Team member role	Perspective
Carer/Alzheimer's Society monitor	<p>I am a Research Network Volunteer and cared for my mother in law who had Alzheimer's Disease until her death in 2016.</p> <p>At the time I became a monitor for the project I knew a lot of carers supporting loved ones with dementia. The purpose of the project really struck a chord with me in terms of how people feel about being carers and how difficult it can be. I knew lots of carers all with differing approaches to their situations. We agreed early on that as monitors we would also be members of the Project Group and this meant that I could contribute my experience to help shape the project. I feel really involved and it's been a very positive experience. I'm delighted to see how the project has progressed. As an added bonus Sahdia and I have co-presented at two events which I think shows a real commitment to involving experts by experience.</p>
Person living with dementia/Alzheimer's Society monitor	<p>To be part of this project has been a joy. To be met by Yorkshire tea on each occasion has made it all worthwhile. The project itself has highlighted some significant finding and the part we've played has allowed us to put our slant on the content. No project should be without people affected by dementia and Sahdia has embraced us fully.</p>
Member of the public	<p>As a member of the Caregiving HOPE panel my role is to support the running of the project from the public perspective as a non carer. I have enjoyed working with the panel to help with the recruitment of participants and the promotion of the study. Our regular panel meetings have provided time for interesting discussions and progress reviews. I have also been able to contribute to academic articles which has allowed me to develop my research skills. Overall, I have found the experience to be very rewarding. The opportunity to understand the research process and to see how the outcomes can be utilised to support people living with dementia and their carers has been very insightful.</p>
Carer support worker	<p>I joined the panel as a BME Dementia worker. My work involves supporting people living with dementia and their carers from BME communities. I became involved as I feel this study would make a huge difference in the life of carers as hopefully they will have more choices and control in their caring roles. Also, I like the fact that this will be looking at cultural issues people face while caring for their</p>

	<p>loved ones with dementia.</p> <p>I have been involved in the project :</p> <p>Recruiting participants to the study</p> <p>Promoting study via social media</p> <p>Attending panel meeting to make sure study is making progress and is on the right track</p> <p>Advising/supporting the study wherever it is necessary</p> <p>It's a very positive experience being involved in this study. As a team member, I have been kept in touch regularly on the progress of study and really looking forward to the final research findings.</p>
Member of the public	<p>I think the study, in the context of current dementia research in the UK, is really paving a positive way towards shedding light on how future carers may be able to cope and potentially what can be done to help them — an often overlooked element in the pioneering edge of dementia research! Being part of this in some small way has been a privilege.</p>